UNIT NO. 6

DYING AND BEREAVEMENT

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ABSTRACT

The relationships between the physician, the dying patient and family members present both challenges and opportunities in communication which the physician may feel ill-prepared to handle. However, dying and the subsequent period of bereavement hold remarkable possibilities and opportunities for growth, which the physician can help materialize with effective communication. In addition, there is evidence for increased morbidity in the bereaved which physicians should be mindful of.

DEFINITIONS

Grief – thought, feelings, emotions and behaviours one experiences with loss.
Bereavement – the situation of losing to death a person to whom one is attached.
Mourning – the process that one goes through adapting to such a loss.

THE CLINICAL TASKS IN COMMUNICATING WITH THE DYING AND SIGNIFICANT OTHERS

Not all people grieve the same way. It may be strong and overpowering for some and a mild experience for others. For some it begins on hearing the news of impending loss, for others, it takes longer to develop. For some, it is a brief experience, for others, it goes on and on and never seems to come to an end.

For the clinician, it is useful to understand and identify the following, in order that greater attention and intervention are provided to those who may benefit.

- mediators of grief response – the relationship with the survivors (Table 1).
- burdens of caregiving – the well-being of the caregivers and survivors (Table 2).
- barriers to a "good death" – the well-being of the patient (Table 3).

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Often, a family meeting is required to clarify the issues at hand and the tasks to concentrate on. Ultimately, the aims are:

- To manage pain and other symptoms.
- To help patient and family adjust to the impending loss.
- To return control to the patient if desired.
- To help the dying disengage from society – to bid farewell to deal with assets and people/events that the dying has responsibilities towards and to reconcile if necessary; and
- To refer to relevant authorities for other assistance if necessary – pastoral staff, social workers, counselors or psychiatrists.

COUNSELLING THE DYING

Despite the arduous nature of the experience of dying, patients can often strengthen bonds with people they love and find profound meaning in their final passage. Basic to this is the recognition of the following needs:

1. Physical needs *"Is there any discomfort that you think I can help with?"*
   When physical needs are not met, it is often difficult to address some of the other aspects of care.
2. Information needs *"Is there anything you wish to ask me regarding your condition?"*
   - Regarding the terminal stages – most people are more concerned about physical distress at the end-of-life than the death itself. Reassurance of support through the dying process will help.
   - Prognosis – the uncertainty needs to be acknowledged but even so, most will appreciate an estimate to be able to plan and to regain some control. It is best not to give a definite figure but a range *"Most people with the same condition may have between 3 to 6 months."*
3. Psychosocial needs *"Are there any worries other than your illness you feel that I can help with?" "Are you coping alright with regards to (e.g. your finances, your children)?" "It may be that a counsellor can help with your children, is it alright if I introduce you to one?"*
4. Spiritual needs *"You have been asking me why this seems to be happening…will you like to tell me about your feelings and thoughts?"*

COUNSELLING THE IMPENDING BEREAVED AND BEREAVED

Mourning does not involve clear cut stages. However, it is helpful to look at it in terms of tasks that need to be accomplished:

1. Accept the reality of the loss or impending loss (e.g. for a

child, to attend the funeral. For an adult, it may be to help acknowledge that the dead person will not return home again).
2. Experience the pain of the loss or impending loss (e.g. putting words to the emotions).
3. Adjust to the environment in which the deceased is not present (may have to start with peripheral issues e.g. to do the income tax, household repairs).
4. Find a way to remember the deceased.

Given the tasks of mourning and the clinical tasks in communicating with the dying and significant others, there are certain implications when dealing with the bereaved and the impending bereaved:

1. Grieving is a normal process and it can occur before a death.
   Recognising this will help facilitate the grief and allow patients and their loved ones cope with their emotions and possible alienation as they deal with the changes. There may be a need to normalise grief reactions – most have no difficulty with sadness, but do have difficulty with anger, guilt and anxiety.

   "It seems that you are angry with what has happened. Help me to understand this." (For a child, it could be getting them to draw a picture of this anger/fear etc).

   In addition, some family members may feel that they are going insane after bereavement and hence, appropriate reassurances should be given to those with sleep disturbances, appetite loss, distractedness and other anomalous experiences e.g. palpitations, "feeling a presence". It is important to acknowledge these reactions first and then "normalise" it so that the bereaved may not feel that physicians are just "brushing it off".

   "You have lost a lot of weight. This must have taken a toll on you. Try and catch a bite when you can. Others in your position have found milk feeds such as Ensure and Isocal helpful till their appetite improves."

2. Encourage communication between patient and family – to express love and gratitude, to reassure and reconcile if appropriate.

   "It may be painful to do so, but he will probably like to hear how you feel about him."

3. After death – encourage reminiscence.

4. Recognise complicated bereavement and make referrals to a professional for further therapy.

Complicated grief

This is a distinct syndrome, separated from bereavement-related depression and anxiety. It may occur when there is a failure of one or more of the "tasks" of mourning. The following are some types of complicated grief and possible management strategies.

- Avoided or repressed grief – guided mourning that encourages the approach to avoided cues in relationship to the dead person.
- Inability to detach from the dead person, often linked to excessive guilt or self-reproach. – saying "good-bye" to the dead person through writing a letter or having an imaginary conversation with the person supported by a therapist.
- Chronic grief or avoidance of a new lifestyle – setting small but progressive goals for change in the context of a therapeutic relationship.
- Grief after traumatic unexpected death – may be associated with post-traumatic stress disorder which requires treatment before dealing with grief reaction.

Special situations

Dealing with collusion

- Recognise and acknowledge that the family or significant others knows the patient better than you. *"You know the patient better than me."*
- Find out the reasons for the fear of disclosure. *"What is it about your father that makes it difficult for you to tell him?"*
- Find out the costs of non-disclosure. *"How has not being able to talk about his illness openly affected you, your father or your family?" or "What would be different if you or your family could have talked about his illness openly?"*
- Reassure family that your duty is not to disclosure to patient beyond what the patient wants to know and is ready to accept.
- Reassure the family that should information be disclosed beyond what they were keen to let patient know – that will be informed, with the patient's consent.

Dealing with the incompetent dying

- Establish the patient's previous stated preferences or values if any. *"Has the patient ever discussed what he would have wanted or not wanted in this kind of situation?" "What kind of person is your father? Do you think he would have wanted you to do this?"*
- Failing to establish substituted judgement, proceed with proxy-decision making. *"As the son, what do you wish for your father at this stage?"*

Dealing with bereaved children

Children express grief and bereavement differently. This depends on the developmental age of the child, significance

of the relationship with the remaining relation, concomitant change in social and financial situation and the emotional climate the child is helped to come to terms with the loss.

- Maintain stability, security and order in lives as much as possible.
- Be certain they are getting attention, love and care – they need time with parents as well as caring adults.
- Reassurance of love and care.
- Talk with them about the dead person – when they want to. For younger children, talking about death and dying can be through play.
- Answer questions honestly and in way they can understand. You may have to do this repeatedly.
- Encourage them to share their feelings with you and help them to express them appropriately.
- Share grief with them. Allow them to comfort you when they want to. Don't hide tears from them – they need to know that crying is appropriate and acceptable. *"We are sad because we will not see grandma again. But we will always remember her."*
- When appropriate, allow them to share in making decisions about their role in attending the funeral and other rituals. Prepare them in advance for what they will see and experience (e.g. at the crematorium and at the columbarium.)

Often, all that is required is active listening (i.e. injecting paraphrasing, acknowledge of feelings, reflection). Most people do find the resources within them and their families to deal with various demands and needs. However, when appropriate, it may be simple problem-solving that the family practitioner can help with or a referral to others who are more experienced.

PITFALLS TO AVOID

- Making assumptions – do not assume emotions on the grieving or bereaved person unless stated by them or that you are sure.
- Saying that you understand – you will not truly understand.
- Telling the person that he or she must be strong (and brave… and not to cry).

APPENDIX

Support Services

1. **Support group for widows (WiCare)**
   PO Box 317
   Ghim Moh Estate Post Office S912741
   Fax: 4632024
   Helpline: C/O Counselling and Care Centre
   Tel: 65366366
   Fax: 65366356
2. **Counselling and Care Centre**
   Blk 536 Upper Cross Street
   Hong Lim Complex
   #05-241 S050536
   Tel: 65366366
   Fax: 65366356
3. **HELP Family Service Center (Help Every Lonely Parent)**
   They provide support/social/educational group for single parent (widow, widowers, divorced parent). They also have groups for children.
   Blk 570 Ang Mo Kio Ave 3, #01-3317
   Tel: 64575177
4. **All Medical Social Work / Care and Counselling**
   Departments of restructured hospitals and national centers.
5. **All family service centers**
   Helpline: 1800-8380100

TAKE HOME MESSAGES

- **Attending to practical issues such as symptom control and coordination of care goes a long way towards alleviating the distress of dying.**
- **Range of patients' and significant others' response to the dying process and bereavement is broad.**
- **Only the minority have pathological coping strategies that will require further professional input.**
- **Often, all that is required is compassionate attention and active listening.**

Table 1. Mediators of Grief Response

Mediators	Risk factors for more difficult grief reactions
Nature of attachment	Attachment is very strong Sense of self-worth and self-esteem in survivor dependent on patient Dependent relationship of survivor on the patient Ambivalent relationship
Mode of death	Sudden death Traumatic death Multiple losses Uncertain losses Geographical distance at time of death
Historical antecedents	How one handled previous losses History of clinical depression
Personality variables	Insecurity Suspicious and non-trusting personality
Social factors	Poor social support Financial difficulty
Number of changes and concurrent stressors	Concomitant life events Concomitant stressors

Table 2. Burdens of Caregiving

Burdens	Risk factors
Time and logistics	Polypharmacy Multiple medical appointments and treatment schedules Dependency
Physical tasks	Dependence in activities of daily living
Financial costs	Direct medical costs Indirect costs through loss of income and benefits
Emotional burden	Intensity of care giving Exhaustion Financial strain Resentment, anger, guilt and sadness
Health risk	Depression Musculoskeletal disorders Cardiac and pulmonary disorders

Table 3. Barriers to a "good death"

Barriers	Risks
Physical discomfort	Poor continuity of care Lack of expertise
Loss of control	Non-disclosure of illness Lack of awareness of patient preferences
Loss of dignity	Dependency in activities of daily living Poor social support Institutional care
Unfinished tasks	Non-disclosure of illness and collusion Sudden deterioration Critical condition
Psychological and spiritual distress	Depression Guilt Anger Lack of access to spiritual and emotional support